The Role of State Public Health Agencies in Genetics and Disease Prevention: Results of a National Survey

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SYNOPSIS

Objectives. The onset and severity of the clinical expression of most diseases that are of public health importance are influenced by genetic predisposition. The ability to assess human genetic predisposition for many diseases is increasing rapidly. Therefore, state public health agencies should be incorporating new developments in genetics and disease prevention into their core functions of assessment, policy development, and assurance. The authors assessed the status of this process.

Methods. The Council of State and Territorial Epidemiologists (CSTE) surveyed states about projects and concerns related to genetics and public health activities. Respondents were the Health Officer, the Maternal and Child Health/Genetics Program Director, the Chronic Disease Program Director, and the Laboratory Director. Where applicable, responses were categorized into assessment, policy development, and assurance functions.

Results. Thirty-eight (76%) state health departments responded. Ongoing genetics activities were assurance (82%), assessment (17%), and policy development (2%). In contrast, Health Officers responded that future genetics activities would be distributed differently: assurance, 41%; assessment, 36%; and policy development, 23%. Future assurance activities would be largely educational. Topics of interest and recently initiated activities in genetics were primarily assessment functions. Funding was the greatest concern, followed by lack of proven disease prevention measures and outcomes data.

Conclusions. State health departments recognize a need to realign their activities to meet future developments in genetics. Lack of adequate resources, proven disease prevention measures, and outcomes data are potential barriers. Public health agencies need to develop a strategic plan to meet the opportunities associated with the development and implementation of genetic tests and procedures.

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INTRODUCTION

Within the next three to five years, the base sequence of all of the genes of the human genome will be known. Consequently, efforts to identify disease-associated gene variants and to describe the influence of the environment on genetic variation are proceeding at a rapid rate; tests to identify asymptomatic individuals with genetic predisposition to particular diseases will continue to proliferate. Once the risk factors that determine disease expression are clarified, clinical and behavioral interventions and environmental modifications may be developed and appropriately targeted to those with genetic predisposition to disease.[1]

Advances in genetics will need to be integrated into public health disease prevention and control activities, which can be categorized into the core public health functions of assessment, policy development, and assurance.[2] Assessment functions identify health problems, identify health resources and evaluate their effectiveness, and present the results to decision makers. Policy development uses the scientific knowledge base in planning, priority setting, allocating resources, and decision-making. Assurance functions provide services necessary to achieve agreed-upon goals. In this context, government agencies are considering their role in genetics and disease prevention. In 1996, the Centers for Disease Control and Prevention (CDC) developed a strategic plan for translating advances in human genetics into public health action,[3] and established the Office of Genetics and Disease Prevention. The National Institutes of Health and Department of Energy Working Group on the Ethical, Legal, and Social Implications of Human Genome Research has developed guidelines to promote safe and effective genetic testing in the United States.[4]

Many state health departments have active and successful newborn genetic screening and other genetic disease prevention programs. However, the scope of such programs is typically limited to diseases related to maternal and child health (MCH); only a few states have developed strategic plans that include a genetic focus on chronic, environmental, and occupational diseases.[5] The Health Resources and Services Administration (HRSA) has recently established an initiative to fund the development of genetic plans that encourage an overarching approach to genetics in 10 state health departments.

To assist state health departments in developing their capacity to translate genetic advances into public health activities, the Council of State and Territorial Epidemiologists (CSTE), a professional organization of epidemiologists practicing at the state and territorial public health level, in collaboration with the Association of State and Territorial Health Officials (ASTHO),

Recent genetics activities in public health

Since the CSTE Genetics and Public Health Assessment Project, HRSA has awarded funds to 17 state public health departments to develop plans for the incorporation and use of genetic medicine and technology. Although this initiative is beginning with collaborative efforts to involve existing programs concerning the early identification of genetic conditions in newborns and children, inherent in this initiative is the need to plan for the integration of genetics within all public health programs.

For example, the Rhode Island Department of Health received a HRSA-sponsored genetics strategic planning grant, and conducted a department-wide effort to raise awareness and explore the relationship between genetics and public health. The RI Department of Health has also sponsored the second annual statewide Genetics and Public Health Conference, and conducted several strategic planning sessions with the participation of staff from all divisions. The Department's genetics strategic plan will focus on infrastructure and resource development and will also establish the Department's role in statewide genetics activities.

ASTHO has formed the Working Group on Genetics and Public Health, with members from the various ASTHO-associated state health professional organizations. ASTHO and Affiliates jointly sponsor, along with CDC, HRSA, and the National Human Genome Research Institute, the National Conferences on Genetics and Public Health. In August, 2000, the CDC Office of Genetics and Disease Prevention and representatives from each of the disciplines in public health met to begin the process of identifying the core competencies necessary for all health professionals to incorporate genetics into public health practice.

Figure 1. Survey questions

Importance of Genetics and Disease Prevention in Public Health

Over the next five years (1998–2002), how important do you think genetic information will become
- — to public health policy,research, and practice? (Form 1)
- — in disease prevention and health promotion programs? (Forms 2 and 3)
- — to your current laboratory activities and services? (Form 4)

What are the three most important areas driving this year's budget? Is a genetic component potentially relevant to any of these?

For the program/activity categories listed below, please name any recently (within the last 2-3 years) initiated activities which, in your area, address genetically-determined disease or include a genetics component. (Forms 2 and 3)
- — Screening
- — Surveillance/Registries
- — Programs

What is the role of the health department regarding genetics? (Form 1)

Areas of interest and concern regarding genetics and public health

Other than current genetics programs, what genetics topics are of interest?

Would any of these be significant concerns were you to consider incorporating new issues in genetics into your section's public health programs and activities? Please rate the significance of each.
- — Lack of funding for genetics components
- — Lack of proven disease prevention measures/outcome data
- — Access to counseling/follow-up
- — Public knowledge re: use of genetic information
- — Health professionals' knowledge re: use of genetic info
- — Lack of population-based data (e.g., prevalence, disease risk)
- — Lack of policies and standards to guide genetic testing
- — Lack of appropriate technology
- — Inadequate legislative protection for genetic information
- — Existing personnel's knowledge/experience

Current genetics and disease prevention staff and programs

Who is the designated Genetics Coordinator in your state? Please provide information on degree, department, and % time spent on genetics. (Form 1)

Do you have staff or contractors who fill the following roles, or memoranda of understanding with any of the following: clinical geneticists, genetic counselors, consultants in genetics. (Form 2)

What genetic services are routinely provided through public health programs and activities in your state, and how are these services supplied? (Form 2)

Laboratory support

For biochemical and hematologic tests that you currently use to detect genetic disorders (e.g., for newborn screening), please check all state laboratory services that apply. For DNA-based tests used to detect genetic disorders, please indicate the current role of state laboratory services, if any, and any future role you envision in your state. (Form 4)

How do you envision regulation of DNA-based testing for genetic disease (e.g. by private laboratories) in your state? (Form 4)

What access does your laboratory have to new tests and methods (such as DNA-based assays for genetic disease)? (Form 4)

Sources of information

In your state, what groups provide assistance or otherwise influence at any level your use of genetic information in public health policy and practice?

Where would you seek further information and experience regarding a topic in genetics that is relevant to your activities?

implemented the Genetics and Public Health Assessment Project in 1998, the results of which are reported here. The goals of the project were to survey state health departments to: obtain information about state programs and activities related to genetics and disease prevention; assess key issues and concerns related to incorporating new genetic information into public health activities; and communicate the findings of the survey to the public health community.

The authors of the present study, who carried out or provided guidance and advice on this project, represent several federal and state agencies and professional societies that share a common interest in the expanding knowledge about human genetics and a desire to help translate relevant information and genetic testing into public health programs. CDC and HRSA programs have already been mentioned. Several states have or are developing strategic plans for genetics. For example, New York has enhanced and strengthened its laboratory permit system to include genetic testing, expanded its research program on human genetics, and begun integration of activities in the Chronic Disease Bureau with those of MCH. CSTE and ASTHO have provided several educational forums in public health genetics for their membership, and are actively promoting activities in this area.

METHODS

Survey design

We designed a survey form to address issues in genetics and disease prevention within the core functions of assessment, policy development, and assurance. Focal areas included new and current activities related to genetics, areas of interest and issues of concern for incorporating genetic information into public health activities, the future importance of genetics to public health programs, and resources for obtaining information about genetics (Figure 1). The basic form was modified slightly for each of the following individuals:

Health Officer/Chief Deputy (Form 1),
Director of MCH/Genetics Programs/ Surveillance/Registries (Form 2),
Director of Chronic Disease Programs/ Surveillance/Registries (Form 3), and
Laboratory Director/Laboratory Services Coordinator (Form 4).

Pilot testing and distribution

We conducted a pilot test of the survey by telephone with eight state health department staff members, two in each of the above-listed position categories. Respondents answered each survey question and commented on wording clarity and focus. We made appropriate revisions based on these comments and mailed revised forms to state and territorial health officers on March 2, 1998, with the request that they be distributed to the individuals listed above. One follow-up telephone call was made and data collection was suspended on June 18, 1998.

Evaluation of responses

Questions required the respondent to either choose an answer from a set of responses on the questionnaire or to provide short, free-text responses. We categorized written responses into the core public health functions and into subcategories of those functions as follows:

- Assessment
  - — Assessing medical and epidemiologic information regarding genetic disease and prevention
  - — Assessing need for specific disease programs
  - — Data collection activities, including surveillance and registries
- Policy
- Assurance
  - — Education
  - — Programs and services

RESULTS

Response

Thirty-eight (76%) state health departments returned at least one form and 26 (52%) returned all four forms. Thirty (60%) Health Officers returned Form 1; 35 (70%) MCH/Genetics Program Directors returned Form 2; 34 (68%) Chronic Disease Program Directors returned Form 3; and 31 (62%) Laboratory Directors returned Form 4. We received no forms from territorial departments of health.

Per capita expenditure for health and hospitals did not differ appreciably across states that returned all four forms ($206), states that returned at least one form ($227), and states that did not respond ($201; the range for all states was $76–$440).[6] Thus, responding states represented all areas of the country and did not differ significantly from nonresponding states in terms of health expenditure.

Importance of genetics and disease prevention in public health

Most respondents regarded genetics as "somewhat important" to "very important" to their activities in the

next five years (Figure 2). MCH/Genetics Program Directors rated the future importance of genetics the highest, followed by Laboratory Directors, Health Officers, and Chronic Disease Program Directors.

All respondents listed their three most important (from a budgetary standpoint) ongoing departmental activities, and noted whether genetics is *or could be* relevant to each activity. Of all genetics-related activities, 17% were assessment functions (Figure 3, "Current activities"), primarily data collection (14%); 2% were policy functions. Eighty-two percent were assurance functions, 76% devoted to public health programs and services, and 6% to educating health professionals and the public.

Thirty-two (91%) of 35 MCH/Genetics Program Directors reported new activities in genetics, compared with 18 (53%) of 34 Chronic Disease Program Directors (Figure 3, "New activities"). Assessment activities included evaluating knowledge of genetics and disease prevention measures (21%), and developing and maintaining data collection programs (38%) such as birth defects registries. New initiatives in policy accounted for only 5% of total responses. New assurance activities were mainly educational programs (21%),focused primarily on health professionals; only 14% of new activities were programs and services.

Health Officers reported on the future role of state health departments regarding the incorporation of genetics and disease prevention activities into public health programs. Thirty-six percent of all responses were assessment functions (Figure 3, "Future role"); only 4%, however, were data collection activities. The majority of proposed assessment activities concerned evaluating knowledge of genetics and disease prevention measures

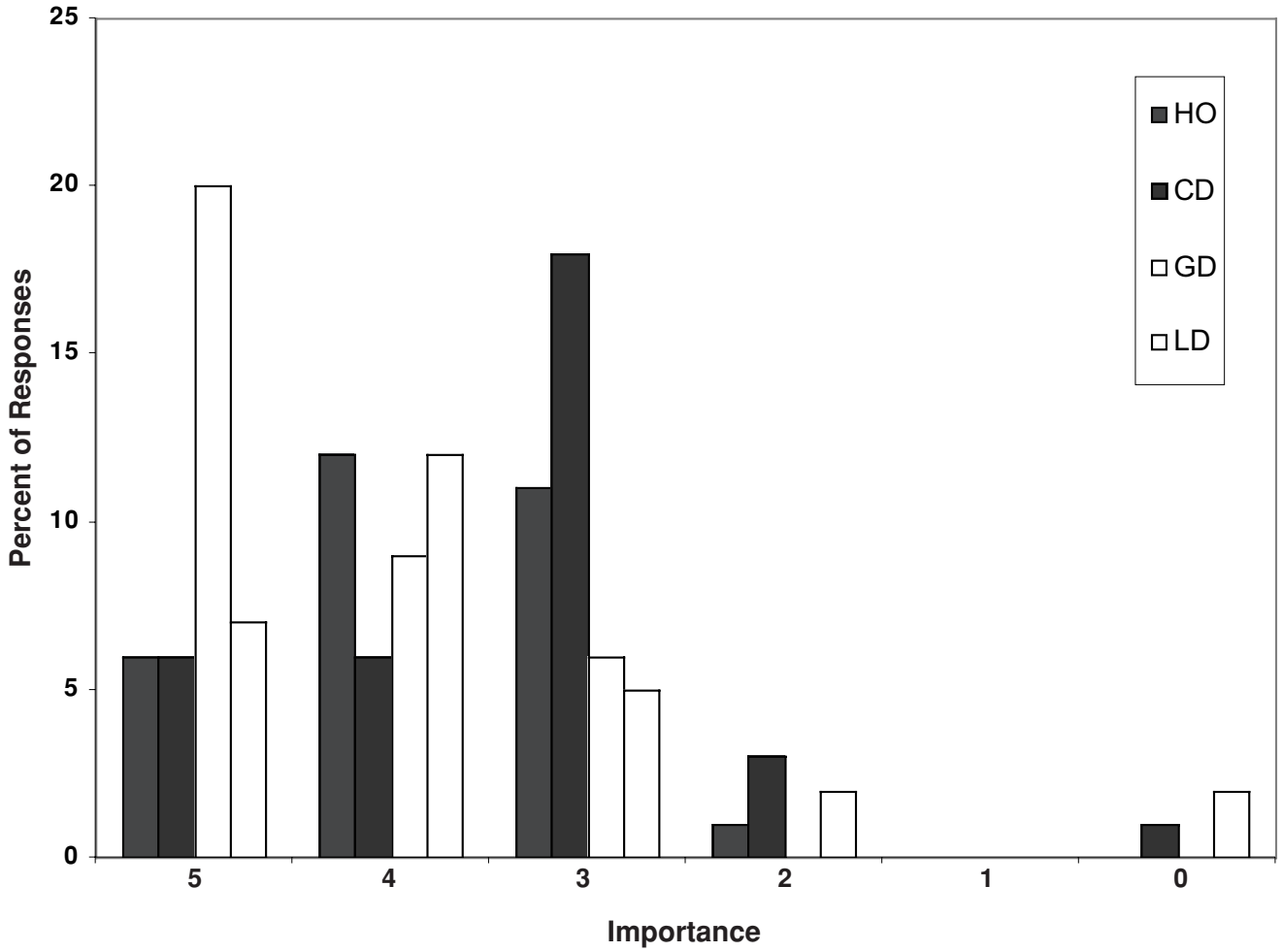

Figure 2. Responses of Health Officers (HO), Chronic Disease Program Directors (CD), MCH/Genetics Program Directors (GD), and Laboratory Directors (LD) to the question: "Over the next five years, how important do you think genetic information will become to public health activities and services?" Importance was ranked on a 5-point scale from very (5) to moderately (3) to not (1) important or unsure (0).

(16%), and evaluating the need for new programs and services (16%). The policy function accounted for 23% of proposed activities. Forty-one percent of responses were assurance functions, and these included programs and services (27%) and education (14%).

Areas of interest and concern regarding genetics and public health

All respondents reported on their specific areas of interest in genetics. Those responses representing assessment functions (53%, Figure 3, "Interest") focused almost entirely on evaluating knowledge of genetics and disease and prevention measures. Policy and assurance (specifically education) functions were reported less frequently by all responders.

All respondents rated the significance of various "concerns" that could make it difficult to incorporate advances in genetics into public health activities. The most important concerns were the lack of funding and proven prevention measures that could guide policy for diseases with a genetics component. In addition, MCH/Genetics Program Directors were concerned with the knowledge base of the general public and health professionals regarding how to use genetic information.

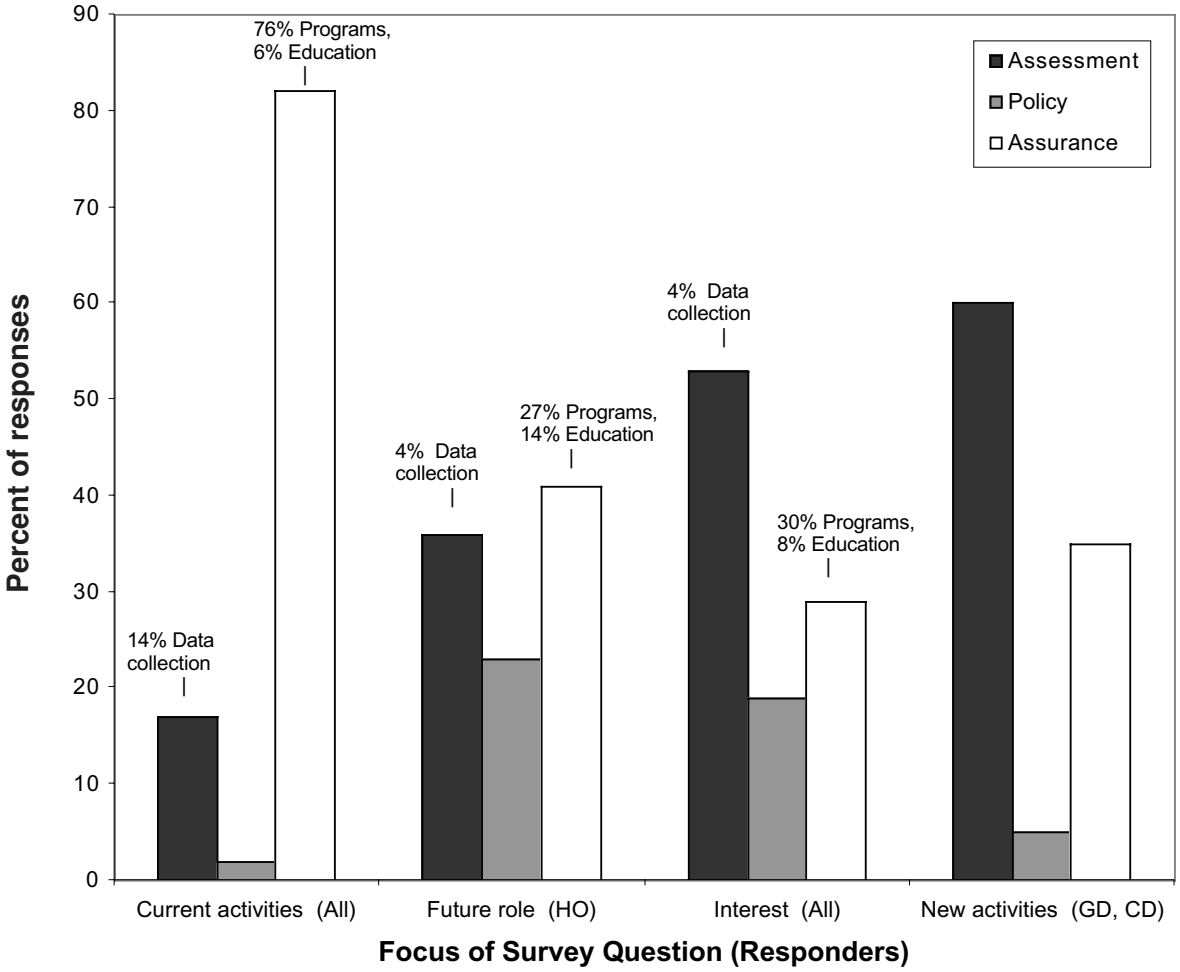

Figure 3. Classification of responses to four survey questions by public health core function. Current Activities: "List three areas of activity that will direct a significant part of your section's overall efforts this year. Is a genetic component potentially relevant to any of these?" (Responses with a genetics component were categorized.) Future role: "What do you view as the role of a public health agency as regards genetic disease and testing?" (Health Officer/HO). Interest: "Aside from currently operating genetics programs, what topics relating to genetics are of interest to you and your state?" New activities: "Please name any *recently (within last 2-3 years) initiated activities* which, in your area, address genetically-determined disease or include a genetics component." (Genetics Directors/GD and Chronic Disease Directors/CD only).

Table 1. Number (percentage) of state MCH/Genetics Program Directors, out of a total of 35 responding, indicating access to genetics-trained health professionals, by method of access

	On staff		*Contractors*		*Memorandum of understanding*	
Type of professional	*Number*	*Percent*	*Number*	*Percent*	*Number*	*Percent*
Clinical geneticists	5	14	31	89	3	9
Genetic counselors	12	34	23	66	3	9
Consultants	11	31	25	71	2	6

Chronic Disease Program Directors identified the lack of policies and standards to guide genetic testing as well as health professionals' knowledge base in genetics as concerns. Health Officers identified the lack of population-based data, and Laboratory Directors were concerned with access to counseling and follow-up.

Current genetics and disease prevention staff and programs

Twenty-three of 29 responding Health Officers reported having a genetics coordinator in their agencies. Of these coordinators, most had postgraduate degrees and dedicated more than 50% of their time to genetics activities. Most MCH/Genetics Program Directors indicated that expertise in genetics (that is, clinical geneticists, genetic counselors, or consultants in genetics) was available to state health departments through contractual arrangements or was present in the current staff (Table 1).

Department of health organizational charts generally showed existing genetic services located in MCH sections, several reporting levels distant from the Health Officer. In addition, MCH reported to the Health Officer through administrative lines different from those used by chronic disease or other departments that might be concerned with future genetic information and activities.

Currently, genetics activities in state health departments center around MCH programs and include some or all of the following: preconceptional counseling, prenatal counseling, prenatal testing, newborn screening, and service delivery to children with special needs (Table 2).

Laboratory support

Approximately two-thirds of responding states provide direct genetic testing services, assessed new tests for use in public health programs, and provided training to other laboratories. Few states performed DNA-based tests; slightly more than half of responding Laboratory Directors have funded or would fund the development of in-house expertise for DNA-based assays for genetic disease. Only three states provided training in DNA-based testing; eight others indicated that they will do so in the future.

Fewer than one-third of responding health departments regulated private genetic testing laboratories, licensed laboratories for testing, or planned to do so in the future. Sixty percent of Laboratory Directors indicated that they believed existing regulations for laboratory testing were sufficient for DNA-based tests for genetic disease, whereas 31% indicated a need for additional regulation for this type of testing.

Sources of information on genetics

MCH/Genetics Program Directors and then Health Officers reported the largest number of groups that influenced their access to and use of genetic information. In general, the types of groups most frequently cited were health department committees or working groups and formal advisory committees, as well as state medical societies or other professional organizations. Health Officers and MCH/Genetics Program Directors also frequently cited nonprofit organizations.

For information sources from which they would seek further genetic information and experience, Chronic Disease Program Directors most often indicated other states, academia, federal institutions, and the scientific literature. MCH/Genetics Program Directors listed numerous other groups, including regional genetics networks, professional genetics organizations, and genetics-related websites.

DISCUSSION

All human disease is the result of interactions between genetic variation and the environment (broadly defined to include dietary, infectious, chemical, physical, and social factors). Examples include phenylalanine and phenylalanine hydroxylase deficiency in PKU, and iron intake and mutations in the HFE gene in hereditary hemochromatosis.[7] The task for public health ge-

Table 2. Number of states (out of a total of 35 responding) with MCH services, by provider and service type

Service	Provider		
	Department of health		
	Direct service	Contracted service	Private organization or **other** state agency
Preconceptional counseling	10	21	14
Prenatal counseling	11	20	17
Prenatal testing	7	15	18
Newborn screening	31	9	1
Services related to children with special needs			
Genetic counseling	10	24	7
Follow-up/case management	17	22	7
Genetic clinics	8	25	6

MCH = maternal and child health

netics is to apply advances in genetics and molecular biotechnology to improving public health and preventing disease.

A framework for applying four essential public health functions in evaluating the relevance of gene discoveries to disease prevention and health promotion was developed as part of CDC's strategic plan for genetics and public health[3]:

> I. Assessment. Surveillance to determine: the the population frequency of genetic variants that predispose people to specific diseases, the population frequency of morbidity and mortality associated with such diseases, and the prevalence and effects of environmental factors known to interact with given genotypes in producing disease. Epidemiologic studies to help understand disease etiology and to develop molecular diagnostics and services for disease prevention and health promotion.
>
> II. Long-term evaluation of genetic tests used in the prediction of genetic diseases to reevaluate policies and recommendations on their use, and the development of model quality assurance programs for genetic testing.
>
> III. Development of intervention strategies for diseases with a genetic component, implementation of pilot demonstration programs, and evaluation of the impact of interventions on reducing morbidity and mortality in the population.
>
> IV. Development and application of communication principles and strategies related to advances in human genetics; the use of genetic tests and services, interventions, and the ethical, legal, and social issues related to these topics.

While public health genetics has successfully focused on programs related to maternal and child health, increasing emphasis will be placed on evaluation and prevention of adult-onset diseases, which will involve new public health departments and staff. The Genetics and Public Health Assessment Project attempted to raise the awareness of public health staff, including those working in the area of chronic disease, to the need to integrate genetics into public health functions; and to determine areas of interest, need, and concern for the task ahead.

We found that public health genetics is well-established in the area of maternal and child health and newborn screening as a result of decades of investment, and programs and services continue to expand. Most responding state health departments employ genetics coordinators and also have access to trained genetics professionals. Not surprisingly, MCH/Genetics Program Directors rated the future importance of genetics highest, followed by Laboratory Directors, Health Officers, and finally, Chronic Disease Program Directors. This may reflect the fact that public health genetics is just beginning to affect the categorically distinct programmatic areas of chronic disease, and environmental and occupational health.

State Health Officers' descriptions of future health department responsibilities in genetics and disease prevention focused to a greater extent on assessment (36%) and policy functions (23%) than ongoing genetics activities (17% and 2%). Similarly, among all respondents, assessment functions accounted for a large share (53%) of topics of interest. Accordingly, recently initiated genetics activities tended to be in the assessment function.

These results suggest that in the future, the distribution of state public health activities in genetics will increasingly emphasize assessment and policy

development. Assessment is especially important for chronic and environmental/occupational diseases for which there are currently less-well-defined heritable components than for genetic diseases currently targeted by MCH. Public health genetics programs may not be appropriate until assessment shows there is high disease prevalence or penetrance, or preventive measures are developed that modify phenotypic expression of genetic components of disease.

In our survey, Health Officers indicated that future assurance activities in genetics were more likely to consist of educational programs, in contrast to current assurance activities that consisted primarily of specific MCH service delivery and prevention programs. As knowledge in genetics is applied to other areas, policy and educational activities take precedence over service delivery and prevention programs.

Changing focus from assurance to assessment activities will require overcoming barriers noted by respondents. Lack of funding for new genetics activities outside of MCH programs was the most important concern for all survey respondents. The HRSA initiative for the development of state genetics plans presents a new and needed funding opportunity that, while focusing on MCH, encourages a more comprehensive approach to genetics planning.

A second major concern was the lack of proven prevention measures and outcome data to justify testing for genetic determinants of chronic disease in population-based public health programs. Although many genetic determinants related to various chronic diseases have been described, additional information will be needed.

Not all states regulate laboratory testing beyond minimum federal standards. Because DNA-based genetic testing has potentially detrimental social consequences, additional regulation has been suggested by various regulatory and advisory agencies.[4,8] The majority of Laboratory Directors in this survey did not regard DNA-based tests as sufficiently different from other types of tests to require additional regulation. Although few states were using or providing training in DNA-based assay formats, many respondents indicated interest in providing such services in the future. New DNA-based testing programs may require the state health department to re-evaluate policy concerning state regulation of genetic testing.

MCH genetics programs are well established in state departments of health. They are expanding their programs in relevant areas of genetics and public health and have access to information, communication networks, and expertise. To what extent can MCH genetics programs serve as models and provide resources for future chronic disease programs related to genetics? According to the organizational trees provided, MCH genetics and chronic disease sections are widely separated on the reporting trees, and may not have established lines of communication. MCH genetics programs focus on screening and individual follow-up while current chronic disease programs are most concerned with population programs that focus on education and behavioral change. There is a clear need for strategic planning and action to coordinate genetics activities in different disease areas within state health departments.

Although the results of this survey are somewhat limited by the response rate, all DHHS Public Health Regions of the United States were represented, and nonresponding states did not appear to differ from responding states in per capita expenditure on health and hospitals. Findings may also have been limited by the interpretation and categorization of text responses.

In summary, the results of this survey indicate that state health departments are becoming increasingly aware of new information in genetics and disease prevention and the potential for its public health impact. To address the results of this survey, we recommend that state health departments adopt the following measures:

- Develop a comprehensive strategic plan for genetics.
- Increase funding for new areas in genetics.
- Develop methods to share existing and future resources in genetics with all program areas.
- Conduct early needs assessments, and plan for policy and program development as new genetic information regarding specific disease areas and prevention measures becomes available.
- Consider the need for state regulation of genetic testing in private laboratories; determine appropriate policy to prevent the undesired use of genetic test results; and analyze new genetic tests for applicability to public health programs.
- Improve the genetics knowledge base of health departments.
- Develop methods to share information among state health departments.

To support state activities, national organizations such as ASTHO and Affiliates, CDC, HRSA, and the American Public Health Association should establish policy statements regarding the effective use of relevant genetic information for health. Such organizations can also help provide training in public health genetics and disease prevention and access to the results of new research. For example, CSTE has orga-

nized a policy steering group to define the role of epidemiologists in developing and supporting comprehensive genetics plans. The Maternal and Child Health Bureau, HRSA, has initiated the formation of a national Newborn Screening and Genetic Resource Center to provide a forum for interaction among consumers, health care providers and researchers, organizations, and policy makers concerned with newborn screening and genetics. CDC provides several training opportunities in genetics and disease prevention,[9] and recently initiated a website for highlighting recent developments in genetics and for presenting organized topic summaries in genetic epidemiology.[10] The First Annual Conference on Genetics and Public Health was held in May 1998. It was jointly sponsored by CDC, HRSA, the National Human Genome Research Institute, and the ASTHO and Affiliates.

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